2016 PROGRESS & 2015 ANNUAL REPORT
FALL 2016

#MORETHANJUSTAWARENESS

A PUBLICATION FOR THE FRIENDS OF:

THECURESTARTSNOW
www.thecurestartsnow.org
Each year The Cure Starts Now funds significant DIPG research in the hope of finding the homerun cure to all cancers. We were ecstatic to present over $4 million in research in 2015 to our grantees in surprise check presentations with our DIPG Collaborative Foundations. This is not only an enormous achievement, it is making significant impact on our researchers understanding the biology of DIPG’s and high grade gliomas, finding their weakness and creating targeted therapies. The impact of the research you are funding became unmistakably apparent when we arrived in Liverpool for the International Society of Pediatric Neuro Oncologists (ISPNO) meeting this summer. Researcher after researcher presented their findings from their studies and the majority of those presentations ended in thanks to The Cure Starts Now and the DIPG Collaborative Foundations. The revelations from their research were only made possible because of charities like The Cure Starts Now, who are willing to fund innovative and out-of-the-box thinking. We are taking risks in confidence that the reward will move us faster towards the cure. With children being diagnosed every day, we cannot wait for government to pass through its bureaucracy. Funding through The Cure Starts Now allows us to fund effectively and efficiently to get results faster.

So as we allowed young researchers to pitch their breakthrough ideas to our esteemed Medical Advisory Council at ISPNO, we were so honored to award a $50,000 grant immediately on site to the winning young researcher who is attempting to find new delivery methods for chemotherapy. It was not only revolutionary but impactful.

We can only achieve this type of nimble and innovative research funding because of your confidence in our funding efforts and ability to bring researchers together. I couldn’t have been prouder of what we have achieved as when I stood face to face with the researchers we have funded and saw their earnest gratitude for our support. Gratitude for finally funding one of the deadliest types of cancer in hopes it will find that home run cure to all cancers. I am honored to pass on their gratitude to you, as it isn’t possible without your support.

From the researchers and families of The Cure Starts Now...thank you!

Brooke Dessercich
Co-Founder / Executive Director
The Cure Starts Now

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### RESEARCH FUNDED

**2008**
- St. Jude — $25,000
- Cincinnati Children’s — $50,000

**2009**
- St. Jude — $10,000
- Cincinnati Children’s — $50,000
- St. Jude — $50,000

**2010**
- Weill Cornell — $91,470
- Cincinnati Children’s — $75,000
- Cincinnati Children’s — $35,000
- St. Jude — $35,000

**2011**
- Sydney Children’s — $100,000
- Doernbecher — $100,000
- Duke Children’s — $82,049
- Texas Children’s — $100,000

**2012**
- Cincinnati Children’s — $219,000
- Stanford University — $35,589
- Texas Children’s — $100,000
- St. Jude — $15,000

**2013**
- Monash Institute — $108,840
- Sick Kids Hospital — $100,000
- Texas Children’s — $100,000
- Dana Farber — $50,000

**2013 CONT.**
- Children’s Cancer Institute — $100,000
- Cincinnati Children’s — $205,000
- Lurie Children’s — $100,000
- Children’s National — $99,979
- Yale — $100,000
- Duke Children’s — $85,394

**2014**
- UCSF — $100,000
- Sick Kids Hospital — $99,400
- Institute of Cancer Research UK — $95,325
- VUMC, Netherlands — $32,529
- Cincinnati Children’s — $176,186

**2015**
- Sick Kid’s Hospital — $190,065
- Stanford University — $200,000
- Centre for Evolution and Cancer — $99,470
- Children’s National — $200,000
- Cincinnati Children’s — $200,000
- Children’s Cancer Institute AU — $145,341
- VUMC, Netherlands — $932,917
- Cincinnati Children’s — $699,935
- Dana Farber — $100,000
- Boston Children’s — $110,000
- UCL Institute of Child Health — $200,000
- Cincinnati Children’s — $100,000
- Children’s National — $125,000
- Texas Children’s — $200,000
- Jewish General Hospital — $100,000

**2015 CONT.**
- Memorial Sloan Kettering — $99,980
- Dana Farber — $100,000
- VUMC, Netherlands — $92,950
- Lowy Cancer Research Centre — $81,683
- Stanford University — $50,000
- Lurie Children’s — $50,000
- Cincinnati Children’s — $100,000

**2016**
- Cold Spring Harbor Lab — $100,000
- Sick Kids Hospital — $194,260
- Children’s Cancer Institute — $143,884
- Gustave Roussy Cancer Campus — $93,071
- Sick Kids Hospital — $50,000

Since 2007, The Cure Starts Now, in conjunction with the DIPG Collaborative, has funded over $7.3 million in groundbreaking DIPG research.

59 GRANTS

The Cure Starts Now, in conjunction with the DIPG Collaborative, has funded 59 innovative research grants in 6 countries.
Amanda “Mandy” Kuck was born in January 2011, just five days before her big brother Ben’s second birthday. Mandy was a very sassy little girl. Her mother used to joke that at 4-years-old she was giving her a glimpse of what it must be like to have a teenager. She was strong-willed and confident. She loved typical girly things like makeup, getting her nails done and shoes. She loved shoes. The fancier, the better! She was goofy too and could easily laugh at herself.

Developmentally, Mandy was on target at each traditional milestone. She never experienced any significant illnesses or injuries. Then in May 2015, things changed. Mandy began to complain on and off of headaches which were accompanied by vomiting. At the same time, her right eye began to ‘wander’ and her gait became increasingly unsteady. As the symptoms progressed, Mandy’s pediatrician sent Mandy to the hospital for a CT scan. The next day Mandy’s parents were told their perfect, happy, beautiful 4-year-old daughter was living with a monster inside her brain: diffuse intrinsic pontine glioma, an inoperable tumor found in the pons of the brainstem.

"That day our family was thrown into the devastating world of pediatric cancer; our lives forever changed. We were told staggering statistics about median survival ranging from 9 to 12 months; children with DIPG have a less than 10% chance of surviving 2 years. We immediately began researching options and treatments," Kimberly recalled.

Mandy underwent two major surgeries within those first three days. On June 15, she took a turn for the worse; her tumor grew and she lost all ability to walk, talk, eat, and communicate.

Mandy was admitted to the PICU at Memorial Sloan Kettering Cancer Center where she began radiation therapy. Only half way through treatment, she gained back all functions except walking. Her parents were excited they got their little girl back and tried their best to enjoy every moment of the summer!

Unfortunately, a mere 7 weeks later the symptoms started to reappear and on August 26, 2015 Mandy was readmitted to Memorial Sloan Kettering Cancer Center. An MRI confirmed what her parents were dreading: tumor progression. Over the next four days, Mandy lost her ability to eat, talk and communicate again.

After Mandy’s diagnosis her parents, Tom and Kim decided they needed to do something after finding out how little funding actually goes to pediatric cancers, especially pediatric brain tumors. In the spring of 2016 they joined forces with The Cure Starts Now as the New York Chapter.

“Being part of The Cure Starts Now allows us to be part of an amazing organization, one that focuses on research, which was extremely important to us. It also allows us to continue to honor Mandy the best way we know how – by raising money and awareness for DIPG,” said Kim.

Although Mandy’s battle ended in January 2016, her legacy – her mark – will live on and continue to inspire others. Even when she could not communicate, she taught those around her to be strong. To be brave. To fight for what they want.

“We do see hope for the future. It’s difficult sometimes but we also made the decision early on that we don’t want to be miserable or sad for the rest of our lives. Mandy wouldn’t want that. If she could go through all that she went through and still manage to smile and laugh, then we can too,” said Kim.

Like all of us, Mandy’s parents are hopeful that in our lifetime, we’ll see more funding, better options and eventually a cure, the homerun cure for all cancer.
Since 2007, The Cure Starts Now has been the leader in non-government funding of DIPG research. Started by brain cancer parents Keith and Brooke Desserich, we have made DIPG our priority.

In the fall of 2015 through early 2016, we wanted to do something special for our 2015 grant winners. We wanted to surprise them and thank them for their continued hard work and dedication to furthering research to find the homerun cure.

So, The Cure Starts Now and members of the DIPG Collaborative set out to 19 institutions in 5 countries to surprise these researchers, Publisher’s Clearing House style!

In the end, over $4 million was granted in groundbreaking research and the reactions were priceless. Each surprise presentation was captured on video and can be seen on The Cure Starts Now’s YouTube channel.

We are often asked how we decide which grants to fund. Easy, we ask the experts. Our Medical Advisory Committee is made up of experts in neuro-oncology from around the world. These researchers review all of the grants submitted and only select the grants that show innovation in their ideas and feasibility in their execution.

Our Medical Advisory Council also reviews grants to ensure there is no duplication of research around the world and that no unnecessary overhead is funded.

To see the surprise check presentations, please visit our YouTube channel at youtube.com/user/curestartsnnow
2015 FINANCIALS

Balance Sheet
For the Fiscal Year Ended December 31, 2015

Assets
- Cash and cash equivalents $1,935,252
- Inventory $55,510
- Other assets - Prepaid expenses $72,770
  Total assets $2,063,532

Liabilities
- Accounts payable $13,103
- Grants payable $1,246,621
- Other liabilities:
  - Accrued compensation $3,863
  - Deferred revenue $45,737
  Total liabilities $1,309,324

Net Assets
- Unrestricted $742,971
- Temporarily restricted $11,237
  Total net assets $754,208
  Total liabilities and net assets $2,063,532

Statement of Activities and Changes in Net Assets
For the Fiscal Year Ended December 31, 2015

Revenue, Gains, and Other Support

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<td>Net assets released from restrictions</td>
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<td>($18,313)</td>
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<td><strong>Total revenue, gains, and other support</strong></td>
<td>$3,490,477</td>
<td>$11,237</td>
<td>-</td>
<td>$3,501,714</td>
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Expenses
Program services:
- Medical research $4,754,376
- Monkey in My Chair $102,618
- Medical symposium $71,099
- Family support program $319,677
- Fundraising $675,510
- Management and general $54,776
  Total expenses $5,978,056

Increase (Decrease) in Net Assets
- Beginning of year $3,230,550
- End of year $742,971
  Total $11,237

Net Assets - Beginning of year $3,230,550
Net Assets - End of year $754,208

* Inventory consists of stocking Monkey in My Chair kits to prepare for demand.
**RESEARCHER Q&A**

We sat down with some of the brightest minds in the cancer research realm and got answers to your questions.

**HAVE** you seen a huge change in the collaborative effort of doctors and researchers 10 years ago versus now?

“I started working on DIPG in 2007. Back then no body was studying DIPG, I think I was one of two or three people. Today, I would say there are probably 30 or 40 researchers around the world that are studying DIPG.”

– Dr. Oren Becher, Duke University
DIPG Collaborative Grant Recipient

**WHY** is the need for private funding so important?

“As you’re aware, federal funding for pediatric cancer in general is a small drop in the bucket of cancer research dollars. Then, taking that down to pediatric brain tumors, it becomes even more fractional.”

– Dr. Stewart Goldman, Robert & Ann Lurie Children’s Hospital of Chicago
CSN Medical Advisory Committee Member

**WHAT** have been some of the most exciting advancements you’ve seen in your field?

“One of the most exciting advancements in the field of neuro-oncology, specifically DIPG work, is that we are now able to understand more about the biology of the tumor.”

– Dr. Trent Hummel, Cincinnati Children’s Hospital Medical Center
DIPG Collaborative Committee Head

**DIPG** is a terrible disease with a 0% chance survival. Do you see hope in any of this?

“I absolutely see hope. We now know a huge amount about the biology. We know that it’s different; we know some of the ways in which it’s different, some of the particular genetic drivers of the disease.”

– Dr. Chris Jones, Institute of Cancer Research, UK
DIPG Collaborative Grant Recipient

**WHY** is collaboration among researchers within the DIPG Collaborative so important?

“We have to work together, this is a small scientific community and whatever resource is available to one researcher should be available to all researchers so we can work together to move forward.”

– Dr. Michelle Monje, Stanford University
CSN Medical Advisory Committee Member & DIPG Collaborative Grant Recipient
MONKEYS GOING VIRAL

See how one monkey went from a classroom star to a social media and television star!

Although Monkey In My Chair has its own Facebook page, one of our monkeys has gone viral and now has her own Facebook page. Cary’s monkey, Coco, arrived in her classroom to help with her time away during treatment. Shortly after Coco made her appearance, the class decided to share her adventures through Facebook. Coco now has her own page, Coco’s Adventures in 3rd Grade, and shares many fun pictures with her followers. Coco has been on mini vacations, watched softball games, went on a poker run, spent a day on a boat, collected Easter eggs and much, much more.

This has been a creative and fun way for Cary to see her monkey, Coco, and what she is up to. Her classmates have been able to take Coco on adventures and share her with their family and friends as well. Coco’s adventures even caught the attention of the local news station who shared her story.

The impact one of our monkeys makes can go a long way, especially when the classroom embraces the monkey and the idea behind it. By interacting with the monkey in the child’s absence, each classmate is able to feel more connected with their friend when they aren’t able to be in the classroom due to a cancer diagnosis.

JOEY LOGANO FOUNDATION FUNDS 133 MONKEYS

The Cure Starts Now is proud to have such incredible donors. Back in July, the Joey Logano Foundation presented The Cure Starts Now with a $10,000 grant to fund 133 Monkey in My Chair kits.

Representatives of The Cure Starts Now Foundation met Logano at the Kentucky Speedway before the Quaker State 400.

“We really want the Joey Logano Foundation to support innovative organizations finding solutions to community issues. We think the Monkey in My Chair program is a unique way to not only help children fighting cancer, but also a unique way to help the child’s school community understand what that child is going through. It teaches compassion and empathy which I think are very important lessons to learn,” said NASCAR Sprint Cup Series Driver, Joey Logano.
#MORETHANJUSTAWARENESS

## CHAPTERS

Mobile, Alabama - Erica Bonner  
Montgomery, Alabama – Elizabeth Adams  
Arizona - Chris Hallsey  
Arkansas – Nicole McCoy  
Australia – Ren Pedersen  
Northern California – Jackie Harrison  
Southern California – Shannen Nelson  
District of Columbia – Neely Agin  
India – Ratesh Khanna  
Indiana – Lynn & John Whittington  
Iowa - Milkinzie Smith  
Kansas – Heidi Feyerherm  
Louisiana – Erin Sarrat  
Massachusetts – Lisa & John Mackintosh  
Nebraska – Jesse Shumaker  
New Hampshire – Alison & Jesse Thompson  
Southern New Hampshire – Frank LaFountain  
New York – Kimberly & Tom Kuck  
North Carolina – Renae & Mark Newmiller  
Ohio – Brooke & Keith Desserich  
Northeast Ohio – Jane Midgley  
Pennsylvania – Alyssa Hawkanko  
Central Texas – Vicky Bridier  
Houston, Texas – Althea Lee  
North Texas – Michelle & Steve Bjornberg  
Southeast Texas – Cristy Smith  
Virginia – Ginny & Dee Pritchett  
Washington - Julie Couture  
Wisconsin - Tricia Verhaalen

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- Tori Glavin  
- Terry Regan  
- Ginny Pritchett  
- Melissa Saladonis

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- Shana Coley, MD, PhD  
- Stewart Goldman, MD  
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- Michelle Monje Deisseroth, MD, PhD  
- Daniel McPherson, PhD  
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- Mark Newmiller  
- Ren Pedersen  
- Erin Sarrat  
- Lynn Whittington  
- Jackie Harrison  
- Heidi Feyerherm  
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- Allyson Richards  
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- Chris Sucher  
- Greg Vehr

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- Nedra Elbl  
- Ken Miller  
- Lisa McPherson  
- Dr. Maria Rapp  
- Dee Watson

#### The Cure Starts Now Staff
- Brooke Desserich, Executive Director  
- Jen Gault, PR & Marketing Coordinator  
- Lisa Hill, Event Coordinator  
- Heidi Feyerherm, Monkey in My Chair Administrator  
- Rick Merk, Development & Family Outreach Coordinator  
- Jeff Branhan, National Race Director  
- Sheila Tillman, Event Coordinator
## INSPIRED GIVING

### 2015 Top Individual Donors* (Donors not listed in alphabetical order)

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<tr>
<th>Category</th>
<th>Donors</th>
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<td><strong>Donors $5,000-$9,999</strong></td>
<td>Alliance Health Sciences, LLC, Arizona Diamondbacks, Big P Crude, Big East Conference, Inc, Charmin - P&amp;G, Connecticut Mason Contractors, Inc, Esther &amp; George Jaruga Charitable Foundation, Ford Motor Company, Greater Kansas City Community Foundation</td>
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<td><strong>Donors $1,000-$2,499</strong></td>
<td>Beacon Consulting Group, CGI, Freedom Title LP, McLendon Real Estate Services Inc., MTX Wealth Management, LLC, Paddles Up, Plante Moran PLLC, ProGen Lab Systems LLC, Stock Yards Bank &amp; Trust, Sunny Delight, Tri-State Roofers Association, J. A. Churchman, Jill Goulait, Thomas Torti, Scott &amp; Eileen Jones, Dave Boyer, David &amp; Ginny Pritchett, Bay Beach Veterinary Hospital, Bloomfield Jr-Sr High School, Children’s Hospital &amp; Medical Center, Cincinnati Bengals, Cincinnati Christian Schools, Columbus Asphalt Paving, Inc, Coop’s Event Barn LLC, Country Chevrolet Buick, Inc, Dentistry At Rea Village, Driving Ambition, Inc., EMTECH Machining &amp; Grinding Inc, Fortner Family, David Frederick, Joseph Gardner</td>
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*Categories are not determined by net value of gifts received.*
**INSPIRED GIVING**

2015 Top Individual Donors* (Donors not listed in alphabetical order)

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<td>Chris &amp; Jim Baumgardner</td>
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<td>Jon &amp; Connie Stiles</td>
<td>Mickey &amp; Larry Samons</td>
<td>Crawl For Cancer</td>
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<td>Jeff &amp; Pamela Murray</td>
<td>Avanti Construction LLC</td>
<td>Pequannock Basketball Assoc</td>
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<td>Yvonne Unger</td>
<td>BW&amp;R, LLC</td>
<td>Stephanie Marsh</td>
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<td>Wells Fargo Community Support Campaign</td>
<td>Children’s Dentistry</td>
<td>International Aviation Support</td>
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<td>Amy O’Keefe</td>
<td>CSX Transportation</td>
<td>Reis Promotions</td>
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<td>Robert Elias</td>
<td>Edmonton Street United Methodist Church</td>
<td>Prograde</td>
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<td>Christine Kress</td>
<td>Geapth Hill Properties &amp; Construction, LLC</td>
<td>John &amp; Nita Arents</td>
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<td>Alice Ravelo</td>
<td>Mason, Schilling &amp; Mason Co., LPA</td>
<td>Oak Hills Local School District</td>
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<td>Elizabeth Sullivan</td>
<td>Mission Pharmacal Company</td>
<td>Books That Heal</td>
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<td>Ohio State Eagles</td>
<td>PNC Institutional Asset Management</td>
<td>Princeton Pike Church of Goc</td>
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<td>Southeastern District Board</td>
<td>Steve Francis</td>
<td>GM Financial</td>
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<td>122 IAABO</td>
<td>Dennis &amp; Margaret Gartman</td>
<td>Joey Logano Charitable Foundation, Inc.</td>
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<td>Virginia Judd Misheff</td>
<td>East Central High School</td>
<td>Milford Youth Soccer Association</td>
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<td>Lucy &amp; Gale Smith</td>
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<td>Norwood City School District</td>
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*Categories are not determined by net value of gifts received.

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**YOUR DONATIONS IN ACTION**

“It was with great delight that I opened my post and found the cheque from The Cure Starts Now Foundation... we can now start working on this exciting project. We are honoured you allow us to use your resources to do this important work.”

- Dr. Karin Straathof
UCL Institute of Child Health, London
What do you do as a volunteer at The Cure Starts Now?

“I started volunteering for The Cure Starts Now several years ago as a “small task” person for the Once In a Lifetime Gala and Auction. I would help with things like wrapping baskets or stuffing envelopes. Now, I do that type of thing for other events, but I primarily spend a few months a year working in the silent auction’s computerized data program; I input donations, group them into packages, write descriptions, and make sure everything is accurate for bidding on the big night!”

Tell me how you first got involved in with The Cure Starts Now?

“My then pre-school aged daughter was diagnosed with an inoperable brain tumor as we were waiting to move into our house 8 years ago. When I went to my son’s kindergarten parent-teacher meeting, I talked to his teacher about the development and it turned out that she was Elena Desserich’s kindergarten teacher as well. She invited me to the gala that year as an attendee and I’ve been involved since!”

What do you do as a volunteer at The Cure Starts Now?

“extraordinary” is fueled by love and selflessness. Volunteering for CSN allows me to witness the love and selflessness of hundreds and sometimes thousands of people each year and it is so good for the soul to see so much good in a life that is hard! I meet fighters and grieving families, hear the stories of other volunteers, see children empty their change purses into donation jars, and receive auction items that are twice as valuable than what we expect because business owners had their hearts touched by the stories of lives cut short, and have waited for gentlemen to stop sobbing before they could donate in honor of their wives and mothers during telethons. This fight matters to so many people!”

What do you think will change about The Cure Starts Now over the next five years?

“I think as the word spreads that historically only 4% of national research dollars have gone to fund pediatric cancer research and, hopefully, the home run cure, people will be fueled to take action both by that injustice and by the amazing things already accomplished through research funded by The Cure Starts Now. So many have already been inspired to help by the passion, and integrity, and mission of this organization, and I think it will continue to grow as people continue look to this organization and its research symposiums to model what effective action looks like. While a ribbon, a color, or a slogan helps raise awareness, I think people really want what CSN has been offering—a focus-driven purpose to cure cancer.”

What would you tell someone who is thinking about volunteering?

“I think all people who have volunteered already know about the sense of personal satisfaction you receive from doing something of significance for others, so I would tell someone thinking about volunteering that it is also FUN! The events across the nation and the world funding research through The Cure Starts Now span many interests—galas, races, beer, wine & food festivals—you name it! I think many people worry that they will have to do a job they feel unprepared to do, but that is not the case—there is something for everyone!”

What might (someone) be surprised to know about you?

“Before chronic conditions forced me to seek other hobbies, I was a violinist and a clogger! Yes, my faulty body has spared you all the sight of me busting a clogger! Yes, my faulty body has spared you all the sight of me busting my Rocky Top routine! Ha!”

What do you do when you’re not volunteering?

“I spend an enormous amount of time in doctor offices and hospitals, mostly for appointments, but also to volunteer in the NICU at UCMC! I also lead a Girl Scout troop, help as a room parent, get my crafty on, love on my family, laugh a lot, and spend time each week wishing I could burn all the paperwork in my life.”